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# Uncovering social structures and informational prejudices to reduce inequity in delivery and uptake of new molecular technologies

Sara Filoche <sup>1</sup>, Peter Stone,<sup>2</sup> Fiona Cram,<sup>3</sup> Sondra Bacharach,<sup>4</sup> Anthony Dowell,<sup>5</sup> Dianne Sika-Paotonu,<sup>6</sup> Angela Beard,<sup>7</sup> Judy Ormandy,<sup>8</sup> Christina Buchanan,<sup>9</sup> Michelle Thunders,<sup>6</sup> Kevin Dew<sup>10</sup>

For numbered affiliations see end of article.

## Correspondence to

Dr Sara Filoche, University of Otago, Wellington 6242, New Zealand; sara.filoche@otago.ac.nz

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## ABSTRACT

Advances in molecular technologies have the potential to help remedy health inequities through earlier detection and prevention; if, however, their delivery and uptake (and therefore any benefits associated with such testing) are not more carefully considered, there is a very real risk that existing inequities in access and use will be further exacerbated. We argue this risk relates to the way that information and knowledge about the technology is both acquired and shared, or not, between health practitioners and their patients.

A healthcare system can be viewed as a complex social network comprising individuals with different worldviews, hierarchies, professional cultures and subcultures and personal beliefs, both for those giving and receiving care. When healthcare practitioners are not perceived as knowledge equals, they would experience informational prejudices, and the result is that knowledge dissemination across and between them would be impeded. The uptake and delivery of a new technology may be inequitable as a result. Patients would also experience informational prejudice when they are viewed as not being able to understand the information that is presented to them, and information may be withheld.

Informational prejudices driven by social relations and structures have thus far been underexplored in considering (in)equitable implementation and uptake of new molecular technologies. Every healthcare interaction represents an opportunity for experiencing informational prejudice, and with it the risk of being inappropriately informed for undertaking (or offering) such screening or testing. Making knowledge acquisition and information dissemination, and experiences of informational prejudice, explicit through sociologically framed investigations would extend our understandings of (in) equity, and offer ways to affect network relationships and structures that support equity in delivery and uptake.

an epistemic injustice—where an individual is not perceived as having the capacity to understand information by another individual, and this affects how, what and if information is shared between them.<sup>4,5</sup> As such, informational prejudice is an experience that is inextricably linked to the social structure within which the prejudice has occurred, and that informational prejudice can be experienced by, and/or between practitioners, and/or by the patients they care for. In this paper, we discuss social relations, and ways to explore them, in knowledge and information acquisition and dissemination as drivers of (in)equitable implementation and uptake of new molecular technologies.

## Health inequities associated with genetic and genomic testing

In many countries across the world, for Indigenous peoples, people of colour and for those living in areas of high deprivation, access to healthcare is inequitable, and health outcomes poorer when compared with the dominant and wealthier population of that country.<sup>6,7</sup> As new molecular technologies are becoming more widely adopted into routine practice, there is emerging evidence that access to, and consequently benefit of, molecular technologies are inequitable.<sup>8–14</sup> For example, despite a known familial risk having been established, African-American women are still less likely to be referred for genetic screening for breast cancer—with some known drivers to this inequity being their healthcare practitioners and the wealth (or not) of the area where the clinic is situated.<sup>9,11</sup> African-American women are also more likely than American women of European descent to receive a result of a variant of unknown significance when they have undergone screening for the presence of *BRCA1/2* variants associated with breast and ovarian-related cancers.<sup>15</sup> Variants of unknown significance are higher in a number of other cancers for people of other non-European ethnicities.<sup>14</sup> In essence, this means for those people who receive a result of variant of unknown significance, there is limited (if no) benefit from ‘personalised medicine’, and as consequence, the potential for driving inequities further is very real. Inequity in delivery and uptake has also been linked to how knowledgeable the healthcare practitioner is about a particular test—with some healthcare practitioners never making referrals for further genetic or genomic testing or screening.<sup>8</sup> For Indigenous populations,

## INTRODUCTION

New molecular technologies hold the promise of great health gains,<sup>1</sup> but also risk exacerbating health inequities if their delivery and uptake is not equitable.<sup>2,3</sup> We argue that this risk is related to the way knowledge about a new technology is acquired, or not, by health practitioners and how, what or if health practitioners then communicate this information to their patients—that is, that the risk is associated with the occurrence of informational prejudice(s).<sup>4,5</sup> Informational prejudice is



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inequity is compounded because the healthcare service can fail to meet their health needs due to lack of cultural responsiveness.<sup>16</sup> Although there are moves to create more culturally responsive services (eg, by having interpreters and including cultural care-takers who act as intermediaries/navigators between the clinic and family(ies)),<sup>17</sup> these initiatives progress at a slower pace than the technologies they are chasing.

### Social view of healthcare, informational prejudices and (in) equity in delivery and uptake of a new molecular technology

A healthcare system can be viewed as a complex social network comprising individuals with different worldviews, hierarchies, professional cultures and subcultures and personal beliefs, both of those giving and receiving care.<sup>18 19</sup> Professional cultures and values are often established during training, with socialisation processes in the ‘classroom’ reinforcing common values, and the language of each profession.<sup>18</sup> With increasing specialisation comes further immersion into the culture of a profession.<sup>4</sup> Epistemology is our way of knowing and our views of knowledge are constructed through our worldview (the lens through which we see and experience the world).<sup>5</sup> To the extent that different people see and experience the world through different lenses, with different interests and cultural frameworks, and the opportunity for epistemic injustice arises. An epistemic injustice is, “*a wrong done to someone specifically in their capacity as a knower*”.<sup>5</sup> Epistemic injustices occur in healthcare contexts as a result of a variety of factors, for example, diagnostic practices and healthcare policies, but the one salient for our purposes is informational prejudice.<sup>4 5</sup> Informational prejudice occurs when a person or group is “*prejudicially judged to lack the ability to provide information relevant in a given context*”<sup>4 5</sup> and they may or may not receive the information they should. When healthcare practitioners are not perceived as knowledge equals, they would experience informational prejudices, and the result is that knowledge dissemination across and between them would be impeded.<sup>20</sup> The uptake and delivery of a new technology may be inequitable as a result. For example, a healthcare practitioner may hold the belief that the science and associated application of genetic testing is a specialist topic, and therefore decide to restrict knowledge dissemination to maintain a position as an ‘expert’. This would exacerbate existing inequities around access to testing and limit adoption of the new technology, especially if a ‘lower status’ group of health practitioners is impeded from accessing technological knowledge and the technology itself. Informational prejudice would also play out between practitioners and patients, where assumptions are made about a patient’s ability to understand information and/or the cultural acceptability of the test for the patient and/or the patient’s ability to pay for the test. The consequence is that a patient may not be enabled to make an informed testing choice. So while new molecular technologies hold the promise of great health gains, their uptake and delivery will be inequitable and existing health inequities will persist if knowledge acquisition and information dissemination are treated as if they are bereft of their social and cultural context.

### Uncovering the social and relational structures, and informational prejudices empirical evidence of uptake and delivery

In order to explore knowledge acquisition and information dissemination in their social and cultural contexts in association with the adoption of new molecular technologies, we argue that a body of work comprising four investigative strands is needed;

namely, social network analysis to elucidate and visualise social structure and function, exploration of how and why knowledge and information is disseminated among healthcare practitioners, empirical evidence on the level of diffusion of the innovation, and an epistemological inquiry of end-users’ experiences of receiving or acquiring knowledge and information. These will now be considered in turn.

Social network analysis is a quantitative approach to analysing social relations, for example, network structure and roles in terms of actors (individual health professionals) and ties (the connections between them).<sup>20–23</sup> With this analysis, the types and characteristics of the relationships between and across different professionals can be explored in great detail (table 1).<sup>20–23</sup> A knowledge broker can be defined as a role that acts as a link between different groups and individuals within a system where they would not normally have a relationship with one another. The defining feature of such a role is to develop relationships and networks with, among, and between people and users of knowledge to facilitate the exchange of knowledge throughout this network and to build capacity to support evidence-based decision-making. In terms of adoption of new technology (eg, a new genetic test within a health system), a knowledge broker could be the link between the laboratory or company and other health professionals. Conceptually, they could also be viewed as opinion leaders or champions.<sup>20–22</sup> Because this role is a prominent position within a network, due to the ability of knowledge brokers to manage the flow of information between various actors,<sup>20–22</sup> identifying knowledge brokers would be a primary outcome measure requirement of the social network analysis, when exploring the adoption and/or use of a particular test(s). The various actors present in the network (eg, healthcare practitioners, ascertained at the start of the social network design process) would be asked to identify which members of the network share information about a particular test(s) with others. The role of a knowledge broker is identified through centrality analysis (ie, betweenness centrality), where the number of times an actor connects pairs of other actors who otherwise would not be able to reach one another (table 1).<sup>20–22</sup> Other structural and relational information from the network analysis such as network density could also be explored as this measure relates to how well the network is co-ordinated.<sup>24</sup> Dense networks are thought to be beneficial for the co-ordination of an activity among actors. However, a major disadvantage of these dense networks is that they can entrench a particular value system and norm. Social networks and structures can therefore reinforce existing informational prejudices, or they can make possible new social relations, which could break down or prevent them.

How and why knowledge is shared is an important consideration in the context of informational prejudices and their occurrence. Knowledge sharing is a fundamentally social phenomenon and inherently relational in nature.<sup>25</sup> Relation models theory claims that people are fundamentally sociable and have certain motivations for sharing (or not)<sup>25</sup>: communal sharing, authority ranking, equality matching and market pricing. For example, “How is knowledge perceived?” can be answered in four different ways—for communal sharing, the answer is: as a common resource, something for sharing; for authority ranking the answer is: as means to display power; for equality matching, the answer is: as a means of exchange for other knowledge; and for market pricing, the answer is: as a commodity which has a value and can be traded.<sup>25</sup> Deciphering the motivations for information sharing could be garnered through in-depth interviews of knowledge brokers and other members as identified

**Table 1** Measures and key characterises used in social network analysis<sup>20 21 23 24</sup>

Global structure: measure	Characteristic Network structural analysis
Cohesion	Describes the interconnectedness of actors in a network. There are three types of measures of cohesion:
Distance	Distance measures the number of ties that separate two actors. If two nodes are directly connected, the distance is one. If these two nodes are separated by one node, the distance is two, and so on.
Reachability	Reachability defines the degree by which a node can be reached by other nodes. If a certain number are unreachable by some actors, it means that the network is fragmented. Reachability corresponds to the number of steps maximally needed to reach from one node to any other node in the network.
Density	Density is defined as the number of existing ties divided by the number of possible ties. Dense networks are thought to be good for coordination of an activity among actors. However, the downside to having dense networks is that they can entrench a particular value system and norm.
Centrality	The degree of centrality represents the number of ties an actor has. If an actor has many ties compared with other actors, this indicates that this actor has a central position in the network. Centrality can also characterise the shape of a whole network. To analyse centrality further, there are three measures:
Degree centrality	Is the sum of all other actors who are directly to a particular actor. It signifies activity or popularity.
Degree closeness	Is based on the notion of distance. If an actor is close to all others in the network (a distance of no more than one), then that actor is not dependent on any other actor to reach everyone in the network.
Betweenness centrality	Is the number of times an actor connects pairs of other actors, who otherwise would not be able to reach one another, and is an indicator of the power that actor has in the network.
Within structure: measure	Network pairwise (between-actor) analysis.
Tie strength	Relates to the intensity of the connection between two actors.
Embeddedness	Is the extent to which network members share common peers, reflecting the number of neighbours that two connected members have in common.
Role and position: measure	<b>Characteristic</b> Network relational analysis
Structural equivalence	Actors that have exactly the same ties to exactly the same others in a network.
Regular equivalence	Less formal than structural equivalence. Actors who are defined as being regularly equivalent have identical ties, but not necessarily to identical others.
Automorphic equivalence	Automorphic equivalence asks if the whole network can be re-arranged, putting different actors at different nodes, but leaving the relational structure or skeleton of the network intact.

from the network analysis, including any members which take a peripheral position.

In order to understand how ‘successful’ the network relations and structures are at enabling the adoption and delivery of a particular test, gathering empirical evidence such as the number of tests delivered, and by and for whom, over time are important metrics to include. Such metrics relate to diffusions of innovation theories,<sup>7 26 27</sup> such as *Magnitude*—the number of network members who have adopted the test, and the number of patients who have undergone such testing; *Speed*—the time to reach a certain level of penetration, has peak adoption rate been reached? *Market share*—to determine which particular test brands are being used. These metrics could then be correlated with those from the social network analysis to explore any interplay with social position, for example, equivalence (table 1). For example, we could interrogate the data to see whether all professionals (eg, general practitioners) are structurally equivalent through their knowledge acquisition/sharing; if they are, do they deliver the molecular test to the same extent, and to whom?

The above three investigative strands are embedded in pragmatic and quantitative paradigms and would only go part way to explaining and understanding how social structures and relationships associated with knowledge acquisition and information dissemination can drive inequity and uptake of a new molecular test. A necessary investigative strand would be one that entails a rich epistemological inquiry of end-users’ experiences of receiving or acquiring knowledge and information in relation to the uptake and offer of a new molecular test. Having this information would enable the appropriate ‘meaning making’ or triangulation of these data as a whole. This piece

of the investigation jigsaw is often overlooked, and by virtue of exclusion only serves to perpetuate epistemic injustice and occurrence of informational prejudice. Of accounts that have explored patient views, or understanding, of a given test (or aspects associated with genomic testing), the study question, and resultant analysis and description, often frames the patients as being the problem, and their level of understanding or views correlated with educational attainment, ethnicity and/or socioeconomic position (or lack thereof)<sup>28–32</sup>—further exacerbating epistemic injustices. Indeed, ‘we’ have a lack of understanding of what informed choice actually means to the people who are undergoing testing or screening, despite health policy(ies) and professional guidelines indicating that it is the responsibility of the practitioner to ensure people make an informed choice to decline, or agree to, testing. Enabling an informed choice in a genomic era is of paramount importance and significance,<sup>33</sup> given the scope of conditions that can be screened for, and the implications surrounding storage of, and access to, and use of DNA information.<sup>34 35</sup> A rich epistemological investigation could be garnered through purposeful sampling and semistructured interviews with practitioners and patients who have experienced the phenomenon of informational prejudice in relation to knowledge acquisition of a new molecular test. For analysis, interpretative phenomenological analysis (IPA) would be a fitting analytical framework as it acknowledges the importance of the social and cultural context, including for Indigenous peoples.<sup>36</sup> *“The aim of IPA is to uncover what a lived experience means to the individual through a process of in depth reflective inquiry... IPA (also) acknowledges that we are each influenced by the worlds in*



which we live in and the experiences we encounter”.<sup>37</sup> Incidences of testimonial and hermeneutical injustices could also be drawn out from the data, for example, by identifying where some patients may experience feeling subordinated to the authority of healthcare professionals.<sup>4,5</sup> To minimise bias, it would be important that the analyses be blinded to sociodemographic information. When exploring the occurrence of informational prejudice, it is also important to be cognisant of the structural prejudices that may be at play.<sup>5</sup> Such structural prejudices are often inflexible, and could include the time allocated for a consultation, because a practitioner may be limited by time constraints to be able to share information in the most appropriate way that is most likely to build a patient’s health literacy.

Informational prejudices driven by social relations and structures have thus far been underexplored in considering (in) equitable implementation and uptake of new molecular technologies. Every healthcare interaction represents an opportunity for experiencing informational prejudice, and with it the risk of being inappropriately informed for undertaking (or offering) such screening or testing.<sup>20</sup> In order to redress health inequities around these new technologies, we need to act fast, and with approaches that are framed sociologically—and which uphold the person that is the patient, at the centre.

#### Author affiliations

<sup>1</sup>Department of Obstetrics, Gynaecology and Women’s Health and Department of Pathology and Molecular Medicine, University of Otago, Wellington, New Zealand

<sup>2</sup>Department of Obstetrics and Gynaecology, University of Auckland, Auckland, New Zealand

<sup>3</sup>Katoa Ltd, Auckland, New Zealand

<sup>4</sup>School of History, Philosophy, Political Science and International Relations, Victoria University, Wellington, New Zealand

<sup>5</sup>Department of Primary Health Care and General Practice, University of Otago Wellington, Wellington, New Zealand

<sup>6</sup>Department of Pathology and Molecular Medicine, University of Otago, Wellington, New Zealand

<sup>7</sup>Christchurch Obstetric Associates, Christchurch, New Zealand

<sup>8</sup>Department of Obstetrics and Gynaecology, University of Otago, Christchurch, New Zealand

<sup>9</sup>Faculty of Medical and Health Sciences, The University of Auckland, New Zealand

<sup>10</sup>School of Social and Cultural Studies, Victoria University, Wellington, New Zealand

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#### ORCID iD

Sara Filoche <http://orcid.org/0000-0002-0874-6494>

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